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ABSTRACT

The research findings of many thanatologists have brought an awareness to the general public that the study of death and dying is an appropriate and instructional need for many people. The attitudes of middle aged and older adults regarding death anxiety, life satisfaction, and locus of control were examined to determine whether adults would change their beliefs after participation in a 12-hour educational intervention module on death and dying. Results indicated that as life satisfaction increased, death anxiety decreased. Respondents in poor health expressed significantly more death anxiety than respondents in good or excellent health. Subjects with higher levels of internal control registered higher life satisfaction. Data collected after workshop participation showed that subjects experienced a significant decrease in death anxiety. (The leader's guide for the workshop and a list of supplementary materials are also included.) (Author/HLM)

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THE INFLUENCE OF AN EDUCATIONAL INTERVENTION MODULE ON DEATH AND DYING ON DEATH ANXIETY, LIFE SATISFACTION, AND LOCUS OF CONTROL AMONG MIDDLE AGED AND OLDER ADULTS IN NORTH CAROLINA

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ABSTRACT

THE INFLUENCE OF AN EDUCATIONAL INTERVENTION MODULE ON DEATH AND DYING ON DEATH ANXIETY, LIFE SATISFACTION, AND LOCUS OF CONTROL AMONG MIDDLE AGED AND OLDER ADULTS IN NORTH CAROLINA

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The primary purpose of the study was to determine whether middle aged and older adults' attitudes regarding death anxiety, life satisfaction, and locus of control could be changed significantly through participating in a 12-hour educational intervention module on death and dying. A second purpose was to determine the extent to which certain personal and situational characteristics of respondents were associated with pretest levels of death anxiety, life satisfaction, and locus of control.

The sample consisted of 207 middle aged and older adults from various sections of the State of North Carolina. The experimental group numbered 94 and 113 people constituted the control group. A special effort was made to insure representativeness in the control group as compared to the experimental group. Special attention was given to such participant characteristics as age, sex, education, income, health, race and marital status. Participation was voluntary.

The study employed the pretest → treatment → posttest design. The experimental group participated in a series of six two-hour workshops entitled "Death--The Fulfillment of Life," designed by the researchers. The control group received no instruction but completed the pretest and posttest.

An adaptation of Templer's Death Anxiety Scale, Neugarten, Havighurst, and Tobin's Life Satisfaction Scale, and Rotter's Locus of Control Scale were administered to all participants in the study as pretests and posttests. Statistical techniques employed included: Pearson product-moment correlation coefficient, least squares means analysis, stepwise regression, and the t-test.

Analysis of the data revealed significant relationships between respondents' pretest levels of death anxiety, life satisfaction, and locus of control and many of the variables examined. Life satisfaction and health were significantly related to pretest levels of death anxiety. As life satisfaction increased, death anxiety decreased. Respondents who considered their health "poor" registered significantly greater death anxiety than those who considered their health "good" or "excellent." Those who thought more frequently about death registered higher death anxiety than those who thought less frequently about it. Respondents who were fearful or depressed, those who felt uncomfortable about talking with others about the other person's terminal illness, and those who were afraid to die had significantly higher death anxiety than those on the other end of the continuum. "Fear of dying" accounted for 42.9 percent of the variation in pretest death anxiety scores.

Four variables were found to be significantly related to pretest levels of life satisfaction (locus of control, death anxiety, frequency of thoughts about death, and awareness of one's own mortality). Respondents with higher levels of internal control registered higher life satisfaction. Those with lower death anxiety had higher life satisfaction. Those who thought least frequently about dying

had higher life satisfaction and those who responded more positively to their feelings regarding their own mortality registered higher life satisfaction.

Life satisfaction and family income were the only two variables significantly related to pretest locus of control. Those with high life satisfaction had high internal control scores. Although the relationship between family income and locus of control was significant, no particular pattern emerged.

The major thrust of the study was to determine whether the educational intervention module could effect changes in death anxiety, life satisfaction, and locus of control. The t-test revealed that no significant changes occurred in levels of life satisfaction and locus of control. However, there was a significant decrease in death anxiety among participants in the workshop and no change in the control group. Two respondent characteristics were significantly related to the change in death anxiety--"fear of dying" and "religious denomination." It was concluded that the educational intervention module did have an impact upon the level of death anxiety within the workshop group but other factors also accounted for some of the variance in change scores.

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Cary Baptist Church
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North Carolina Agricultural Extension Service
Western Carolina University

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*National Retired Teachers Association/American Association for Retired Persons

SUMMARY AND CONCLUSIONS

Purpose

The primary purpose of this study was to determine whether middle aged and older adults' attitudes regarding death anxiety, life satisfaction, and locus of control could be changed significantly through participating in a 12-hour educational intervention module on death and dying. A second purpose was to determine the extent to which certain personal and situational characteristics of respondents were associated with pretest levels of death anxiety, life satisfaction, and locus of control.

More specifically, the study addressed the following research questions:

1. To what extent are selected personal and situational characteristics of respondents related to their pretest levels of death anxiety, life satisfaction, and locus of control?
2. Can middle aged and older adults' attitudes regarding death anxiety, life satisfaction and locus of control be changed significantly through participating in a 12-hour workshop on death and dying?

Background and Need for the Study

The subject of "death and dying" has become less a taboo topic due in part to the research and public discussions of Kubler-Ross (1969), Kastenbaum and Aisenberg (1979), Green and Irish (1971), Kalish (1963), and many others. These thanatologists have produced impressive research findings and have brought to the attention of the

general public an awareness that the study of death and dying is an appropriate and instrumental need for many people.

The study of death has been a part of all societies and a major subject of study for theologians, philosophers, psychologists, sociologists, and physicians. The 20th century has brought tremendous strides in lifesaving and life-maintaining technologies. We are living longer than ever and we are preventing disabling diseases from attacking us with more proficiency than ever before. However, there seems to be a corresponding increase in many people's inability to cope with the death experience. The denying of one's own inevitable death seems pervasive in our society--a defense mechanism that appears to be causing more anxiety than comfort (Kubler-Ross, 1969; Hinton, 1973).

Death is a biological and existential fact of life that affects every human being. According to Robert Atchley (1972), middle age is the time when most people come to grips with the fact that death is real, and not just something that happens to someone else. Gail Sheehy (1974, p. 10) describes the feeling she had when she suddenly realized that she was facing her own death as "something alien, horrible, unspeakable but undeniable . . . my own death." She believes that each of us stumbles upon this issue in midlife and that we must learn to live with it. It is no easy task to accept this reality, and Sheehy (p. 10) states, "We try to flee the task of incorporating our own shortcomings and destructiveness, as well as the world's destructive side. Rather than accept the unacceptable spooks, we try to drive them away by resorting to the coping techniques that have worked before."

Koller (1968, p. 107) recognizes that "Certainly one of the most difficult problems in living is to come to grips with the inevitability of one's own demise. In this mental exercise individuals develop various ways of turning away from their involvement in life. Each settles upon some pattern that will enable him to be functional despite the certainty of eventual loss of his conscious self. Perhaps no other pattern reflects more of the personality organization than the manner in which a person approaches his own death."

Research on the personal and situational variables related to death anxiety have not yet produced clear-cut findings. Rather, there appears to be a series of contradictory conclusions based on such factors as age, residence, life satisfaction, locus of control, sex, health, age of death of parents and kin, religion, marital status, income, education, and fear of death.

Research Procedures

The sample consisted of 207 middle aged and older adults from various sections of the State of North Carolina. The experimental group numbered 94 and 113 people comprised the control group. A special effort was made to insure representativeness in the experimental and control groups on such participant characteristics as age, sex, education, income, health, race, and marital status. Participation was voluntary.

The study employed the pretest→treatment→posttest research design. The experimental group participated in a series of six two-hour workshops entitled "Death - The Fulfillment of Life." The control group received no instruction but completed the pretest and posttest.

The workshops were conducted by the researchers and several leaders trained by the researchers.

The workshops offered participants an opportunity to learn about many facets of the "death experience," interact with other participants relative to their own feelings about death and dying, and provided experiences and exposure to positive options for later life. The learning experiences consisted of lecture-discussions, audio-visual presentations, group discussions, case studies, and sensitivity exercises.

Pretests and posttests were administered to the experimental and control groups. Scales used to measure levels of death anxiety, life satisfaction, and locus of control were: an adaptation of Templer's Death Anxiety Scale, Neugarten, Havighurst, and Tobin's Life Satisfaction Scale, and Rotter's I-E Scale.

The major statistical techniques employed were: Pearson product-moment correlation coefficient, least squares means analysis, stepwise regression, and the t-test.

Results and Conclusions

The pretest mean scores indicated that, as a group, the participants in this study were somewhat low in death anxiety, relatively high in life satisfaction, and relatively high in their sense of internal control. It should also be noted that, generally, the participants were mostly white persons who had above average education, good health, and were from the middle to high income bracket. Due to the heavy concentration of persons possessing these latter characteristics, one may need to be cautious as he or she attempts to generalize the results of this study to other groups of persons.

Life satisfaction and health were two variables which appeared to be significantly related to death anxiety. As life satisfaction increased, there seemed to be a decrease in death anxiety. This was contrary to previous research (Bell and Batterson, 1979; Nelson, 1974) which had indicated that persons with high life satisfaction exhibited higher death anxiety. It just may be that persons who are satisfied with life do have a sense that their lives have meaning and purpose--in Erikson's terms, they have ego "integrity"--and, therefore, they can face the ultimate that life has to offer--death--without a sense of fear. They do not have to fear death, for they can feel that their being here is worthwhile and satisfying. Another explanation for the relationship between death anxiety and life satisfaction could be that persons who are satisfied with life are so busy enjoying life that they just do not have time or do not take time to worry about death. Their attention is so centered upon enjoying the life they are living today that death and the anxiety surrounding it just do not impinge upon their consciousness.

As participants' health was viewed as being progressively poor, death anxiety increased. The earlier research regarding health and death anxiety reported conflicting results. The finding of this work is consistent with the research of Christ (1961) and Rhudick and Dibner (1961), but is inconsistent with the work of Bell and Batterson (1979). Persons who see themselves as having poor health are probably more conscious of the fact of death, and, therefore, they tend to be more anxious about death.

Locus of control, age, sex, religiosity, race, religious denomination, education, family income, marital status, and occupation did not appear to be related to death anxiety.

Four responses to questions pertaining to attitudes about death were significantly related to death anxiety:

(1) The more frequently persons thought about dying the higher was their death anxiety.

(2) Persons who were "fearful" or "depressed" when they thought about dying had the highest anxiety, while those who felt "resolved to accomplish something in my life" or who felt "pleasure in being alive" had lower death anxiety.

(3) Persons who had a lower death anxiety felt more comfortable in talking with a close individual about that individual's terminal illness than did persons who had high death anxiety.

(4) Those who were afraid to die had a higher death anxiety score than those who were not afraid to die.

The variables studied in this research project accounted for 69.8 percent of the variation in the death anxiety scores. The question "I am not at all afraid to die" accounted for the greatest amount of variation (42.9 percent) in death anxiety scores.

Of the respondent characteristics, only two appeared to be related to life satisfaction--locus of control and death anxiety. The more individuals felt that they controlled their own lives, the more satisfied they were with life. This finding is consistent with what was expected based upon the literature review (Palmore and Luikart, 1972; Trent, Glass and Jackson, 1978). As death anxiety decreased, life satisfaction tended to increase. This latter finding was expected based upon the earlier discussions regarding life satisfaction and death anxiety.

Health, education, family income, occupation, sex, race, age, religious denomination, religiosity, and marital status appeared to have no significant relationship to life satisfaction.

Two responses to questions pertaining to death were significantly related to life satisfaction. Generally, those persons who thought less frequently about death appeared to be more satisfied with life. The one exception to the pattern was that those who "frequently" thought about death had a slightly higher life satisfaction mean score than those who "occasionally" thought about death. Persons who were able to respond more positively to the question, "When I think of dying or when circumstances make me aware of my own mortality, I feel . . .," had higher life satisfaction mean scores than those who responded negatively.

The question relating to whether or not one was afraid to die was not significantly related to life satisfaction.

Approximately 47 percent of the variation in life satisfaction scores were accounted for by the variables utilized in the analysis; however, no one variable appeared to account for a substantial amount of the variation. Further study is needed in this area.

Life satisfaction and family income were the only variables which seemed to be related to locus of control. In the previous discussion, when life satisfaction was the dependent variable, a relationship was found between locus of control and life satisfaction. It was expected that there would be a relationship between the two variables when locus of control was the dependent variable. The more satisfied persons were, the more those individuals felt that their lives were internally controlled.

While family income was related to locus of control, it is difficult to explain the relationship. There does not appear to be any clear pattern regarding level of income and whether or not one feels

his or her life is internally or externally controlled. Most earlier studies (Trent, Glass and Jackson, 1978; Kreps, 1971; Neugarten and Maddox, 1978; Schultz, 1974) had indicated that persons who had higher incomes tended to feel that they were more internally controlled than those who had lower incomes; though there was one study (Nehrke, Bellucci and Gabriel, 1978) which had indicated the opposite relationship might be true. The present study only adds to the conflicting situation regarding relationship of family income to locus of control.

No significant relationship was found between locus of control and death anxiety, religiosity, education, sex, race, age, religious denomination, health, marital status, occupation or any of the questions about death used in this study. The variables analyzed in this project accounted for 36.2 percent of the variation, but no one variable contributed a substantial amount to the variation.

The primary emphasis of the research project was to determine whether middle aged and older adults' attitudes of death anxiety could be changed significantly through participating in a 12-hour intervention module (workshop) on death and dying. The results demonstrated that death anxiety could, indeed, be decreased a small, but significant, amount through participating in the workshop. There was no significant change in death anxiety within the control group. It could be concluded that the intervention module (workshop) as developed and conducted, would be a useful educational activity for reducing death anxiety in adult groups with similar characteristics to those participating in the study.

A second, but lesser, emphasis of the research was to determine whether middle aged and older adults' attitudes of life satisfaction

could be changed significantly through participating in the instruction module on death and dying. It was anticipated that there would be an increase in life satisfaction among the workshop participants and no change in the control group. Although participants in the workshop showed a slight increase in life satisfaction from pretest to posttest, the change was not significant at the level chosen for rejecting the hypotheses. There was a slight but smaller nonsignificant increase in life satisfaction within the control group. It could be concluded that life satisfaction, as measured by the scale used in this study, may have been affected differentially by the subject matter addressed in the instruction module. Also, the length of the workshop was perhaps too short and interaction too limited to make a significant impact on such a broad concept as life satisfaction. It was concluded that the instruction module was not effective in influencing a significant increase in life satisfaction among the workshop participants.

A third and also lesser emphasis of the research was to determine whether middle aged and older adults' attitudes of locus of control could be changed significantly through participating in the intervention module on death and dying. It was expected that participants in the workshop would show an increase in internal control even though research presents conflicting evidence. The workshop was designed to bolster maintenance and coping skills in one important area of life. The results of the study did not support the conceptual framework established for the study. There was no change in mean internal-external locus of control scores from pretest to posttest among the participants in the workshop. The non-participants showed a slight,

but nonsignificant, decrease in internal control. It was noted that both groups--experimental and control--exhibited very high levels of internal control (12.559 and 12.423, respectively) prior to the workshop. The fact that the pretest scores were so high may have limited the potential for further increase in internal control. It was concluded that the instruction module had no significant impact upon participants' locus of control.

The last section of the data analysis focused on the relationships between changes in death anxiety and personal and situational characteristics of respondents participating in the workshop. As there were no significant changes in life satisfaction or locus of control from pretest to posttest, it was decided to examine the data to determine what factors other than the workshop experiences were related to the decrease in death anxiety within the experimental group.

The least squares means analysis showed that 50 percent of the variance in difference scores in the experimental group were accounted for by the variables in the linear model. Only two respondent characteristics were significantly related to the decrease in death anxiety--"fear of dying" and "religious denomination." Two additional respondent characteristics--"ease one felt in talking with someone else about their terminal illness" and "marital status"--approached a significant relationship with change in death anxiety. Both factors should be explored further in future studies. It was concluded that factors other than the workshop accounted for much of the change in death anxiety within the workshop group, but the workshop itself did have a decided impact upon change in death anxiety.

IMPLICATIONS

The results of this study have important implications for educators, institutions, organizations, and state and federal government agencies concerned with enhancing the quality of the adult life. The major focus of this study was to see if death anxiety could be reduced through a planned educational experience. This study has demonstrated the effectiveness of a particular unit on death and dying in changing death anxiety in volunteer adult audiences. While further evidence needs to be gathered regarding its effectiveness with different groups of adults, it would seem that this workshop, in its present form, could be used with similar groups throughout the country to lower death anxiety. It would seem that the methodology and materials could be used with some confidence in other situations until the workshop has been tested in those situations.

The fact that the leader's guide for this workshop was designed for lay leaders implies that this workshop can be planned and conducted without the leader being an "expert" on the subject of death and dying. This should make the workshop more readily accessible to various adult groups. It is true that lay leaders could become involved in topics which might be beyond their ability to handle; however, it is believed that the detailed instructions and the suggested resources provide a framework which should keep the learning experiences within a "manageable" emotional level for most adults. The nature of the leader's guide should mean that the workshop could be used extensively by many groups in North Carolina and the U.S.A. The short time required for the workshop should enhance its attractiveness to potential audiences.

It should be of interest to educators that attitudes toward death (death anxiety) can be changed significantly over a relatively short period of time (six weeks) through educational experiences designed specifically to change death anxiety. This change seemed to occur in one course of study over a six-week period. It is exciting to imagine what might happen if death education could become a part of all individuals' learning experiences throughout their lives.

The approach used in this study has potential for adaptation to other subject areas where attitude change is a major objective. If attitudes toward death anxiety can be lowered, perhaps other attitudes can be changed in a positive direction through similar means.

The findings of this study should contribute to the body of knowledge relating to continuing education for adults and to attitudes and attitude change. The fact that the variables identified in this study accounted for 69.8 percent of the variance in death anxiety scores should be of value to researchers. In addition, the research methodology of this study might serve as a guide for future research involved with attitude change.

The profile data of the participants in this study should provide some clues to adult educators as to the kinds of persons who volunteer for learning experiences relating to death and dying. Such an analysis should suggest prime target groups for death education. In addition, a study of the profile should also provide clues to the kinds of persons who may not attend death education experiences on a volunteer basis. The latter study might provide a starting point for educators to consider alternative delivery systems for death education.

It may be that the greatest value to be derived from a workshop on death and dying is that such a learning experience brings people to the point of confronting the inevitability of their own death. Perhaps, over time, such an experience will aid individuals in re-thinking the meaning and purpose of their own lives. A positive resolution of this process, perhaps, can help persons move toward self-fulfillment, greater happiness in life, and maybe equip them to assist others in the process of facing the fact of death.

RECOMMENDATIONS

Based on the findings of this study, it is recommended that the leader's guide used in this study be produced in a format and in quantities which can be readily available for widespread use. It is further recommended that the findings of this study, along with the availability of this unit, be widely circulated to persons such as directors of continuing education in colleges and universities, technical institutes and community colleges, denominational religious leaders, persons concerned with aging in the Agricultural Extension Services in the various states, administrators of retirement complexes and nursing homes, program directors of such organizations as hospices, etc.

It is recommended that further research on attitudes toward death and dying be conducted and educational programs be developed and evaluated as to their effectiveness in changing attitudes among the various age groupings in society. The following research projects are recommended:

1. Conduct this same study with other more representative samples of adults.
2. Conduct a longitudinal study to determine whether attitudes concerning death and dying change as persons move through the life span and to determine what variables may be related to different attitudes at different points of the life span.
3. Adapt this workshop material for use with children and youth in the public schools and conduct research to determine if

their attitudes can be changed through participation in the learning experiences.

4. Build in a follow-up death anxiety measurement (after four to six months) into future studies on attitude change to determine if the change in death anxiety persists over time.
5. Conduct a study which measures the effectiveness of two or more educational methods in changing death anxiety.
6. Conduct a study to determine what, if any, influence the death anxiety attitudes of the workshop leader have on the amount of change occurring within the workshop participants.
7. Conduct a study to determine what, if any, effect a workshop on death and dying would have upon the attitudes and performance of health care professionals who daily relate to dying persons.

Leader's Guide for Workshop:

Death - The Fulfillment of Life

Workshop

DEATH - THE FULFILLMENT OF LIFE

Purpose

The purposes of the workshop are to help participants become better able to discuss the topic of death; to provide them an opportunity to examine their own attitudes toward death and to develop a philosophy of living.

Outline

Session I:

The Meaning of Life and Death

Aims: To help participants:
(1) Understand some of the feelings and attitudes regarding death and dying prevalent in today's society.
(2) Examine their own feelings and attitudes toward death and dying.
(3) Understand that the meaning life has for an individual is related to the meaning death holds for that individual.

Session II:

Customs Surrounding Death

Aims: To help participants:
(1) Recognize the universal human need for symbolic rituals in dealing with death.
(2) Understand some of the motives underlying cultural practices surrounding death in the United States.
(3) Understand that the customs and rituals surrounding death reveal an individual's or society's philosophy about death.
(4) Become more open in their willingness to discuss the topic of death through the sharing of feelings with other participants.

Session III:

Stages of Death and Dying and Alternative Care

Aims: To help participants:
(1) Understand the various stages of the dying process and realize that these stages are experienced by most people.
(2) Become aware of various caregivers involved in the dying process.
(3) Reflect on how alternative care systems might help in the acceptance of death.

Session IV:

Handling Grief

Aims: To help participants:
(1) Understand the meaning of grief.
(2) Understand the stages of grief.
(3) Examine their own feelings about grief.
(4) Become aware of roles that caregivers may assume with those in grief.

Session V:

Choices about Life and Death

Aims: To help participants:
(1) Understand their choices in determining how, when and where they wish to spend their last days or years.
(2) Examine their own attitudes and feelings about euthanasia.
(3) Become familiar with the "Dying Person's Bill of Rights" and the "Living Will."
(4) Become familiar with the hospice movement and its development.

Session VI:

Decisions in Life about Death

Aims: To help participants:
(1) Become more aware of many of the details involved in the dying process: estate planning, funeral arrangements and family affairs.
(2) Understand that through a fulfillment of life, death can become a fulfilling experience.
(3) Reach a closure between their past and present feelings about death and facilitate plans for the future.

Death the Fulfillment of Life

SESSION I

How Do You View Death?

Aim:

To help participants:

(1) Understand some of the feelings and attitudes regarding death and dying prevalent in today's society.

(2) Examine their own feelings and attitudes regarding death and dying.

(3) Understand that the meaning life has for an individual is related to the meaning death holds for that individual.

Resources Needed:

"Workshop Outline"
Materials for name tags--construction paper or 3 x 5 cards, felt markers, masking tape or straight pins
Cassette tape player
Cassette tape with songs about death
Information Sheet 1, "Songs about Death"
Information Sheet 2, "Death Ceremonies"
Information Sheet 3, "Philosophies of Death"
Information Sheet 4, "Bibliography of Readings"
Questionnaires about death and dying
Filmstrip, "Walk in the World for Me"
Filmstrip projector, screen
Manila envelope

Room Arrangement:

If possible, the room should be arranged with chairs around tables or in a semi-circle, in order to encourage discussion.
The filmstrip projector and screen should be set and ready for showing.

Teaching Plans for Session:

A. Name Tags (Do this as persons arrive, prior to the announced starting time.)

Prepare name tags out of construction paper or 3 x 5 cards. Have persons print their names on the name tag with a felt marker. Ask them to print large enough for others to read at a distance. Use masking tape or straight pins to stick the tags to the person.

The leader should help the first two persons who arrive to prepare their name tags. Ask those two people to help the next two people to get a name tag. Urge them to use that time to get acquainted with those persons. Then those two could help the next two, and so on. This "each one help one" technique should help the group members to begin to relate to a person or two. It will give individuals something to do as they enter and it should begin the process of creating a comfortable climate for learning.

B. Introduction (30 minutes)

At the announced starting time for the session, the leader might get the attention of the group and introduce the six-session study in this manner:

"For six sessions we will be studying the topic of death and dying. While this is not an issue that most of us like to talk about, it is an area which all of us must face during some time in our lives--whether it be our death or that of a person close to us. We will have an opportunity to learn about many different facets of the 'death experience.' We will be able to interact with others about our feelings and experiences. We will look at some positive alternatives which should help us as we have to deal with death and dying.

"It is important to mention, at this point, that there is the possibility that some very sensitive emotions may arise during the course of this study. For some persons these emotions may be too painful to deal with. Unfortunately, we are not equipped to deal with persons who would have extreme difficulty in handling their emotions about death. If you feel uncomfortable about participating in any activity, please feel free to leave at any time.

"This series of workshops was developed at North Carolina State University as an attempt to help adults become better informed about death and be better able to cope with it. In an effort to determine if these workshops are effective, we need your help in filling out some forms. These are not tests, but are a means by which we can see if the learning experiences have any effect on what we think about death and dying. These forms will give us an understanding of what individuals feel about life and death and of various factors related to life and death. Some parts of these forms will be administered again at the end of the six sessions and the results will be compared with the first session to see what changes have occurred.

"At the end of the learning sessions, we need to be able to identify each person's forms and keep them together. You can facilitate this process if you will put your social security

number or phone number on the first page. We will ask you to do the same at the end of the course. There will never be any attempt to try to identify any of this information with a particular name. This is only a way to keep the proper information grouped together. Your participation in this part of the project will help give some insights into the effectiveness of this workshop. You will help strengthen the workshop and help contribute to others who may participate in a similar workshop in the future."

As the individuals hand in their finished papers, place the forms in a large manilla envelope. Give each student as he/she finishes the paper a copy of Information Sheet 1, "Songs about Death."

C. Music Activity (15 minutes)

"Music is very revealing. It reflects the pleasures, anxieties, concerns, problems, and doubts of people. Listen to the following songs about death and follow the words on the information sheet. While you are listening, think about these questions:

1. How is death pictured in these songs?
2. Do you agree with the images of death portrayed here? Why or why not?"

As a total group, listen to the songs. Following the presentation of the songs, divide the total group into smaller groups of three per group. Restate the two questions and ask them to discuss the questions.

D. Discussion Activity (20 minutes)

After about ten minutes in the small groups, come together as a total group to discuss the questions. Spend a brief amount of time on question one, but spend a greater amount of time with the second question. The purpose of this portion of the session is to help the group members to verbalize and examine their own thoughts and feelings regarding death and dying. For many individuals, this may be the first time they have tried to put their thoughts into words for other persons. Some other questions which may help this discussion are:

1. How do you view death? What is the meaning of death for you?
2. What do you think has most influenced your views about death?
3. Why do you think people fear death?
4. What do you fear most about death?

You may not be able to deal with all of these questions because of time limitations. Use those which seem most appropriate within the time constraints you face.

E. Death Philosophy (15 minutes)

To make the transition from the previous discussion to this portion of the session, the following statement might be helpful:

"For the last few minutes we have really been discussing what might be called our own philosophies regarding death. Dr. Venus Bluestein, who teaches death education courses at the University of Chicago, has a very brief statement regarding her own philosophy about death. I wonder how you react to her thoughts:

"My own orientation is, to put it quite briefly, that death education helps one to live this life more fully and meaningfully. When one accepts that he will die, that his life is finite, that he cannot choose how and when he will die, but that he can choose how he will live--he gains a different perspective on life; relationships take on a new meaning; one develops a different set of priorities; one constantly questions--how do I wish to spend my life? What are the really important things?"

After the group has had a brief time to initially react to the statement, you might pose the following questions:

(1) Do attitudes about death have an effect on how one views life?

(2) Do attitudes about life have an effect on how one views death?

Very little time needs to be spent on discussion of these questions. They are really more for reflection than discussion.

F. Show the Filmstrip, "Walk in the World for Me" (30 minutes). Introduce the filmstrip to the group. The following statements might be used: "In this filmstrip Doris Lund, author of the book Eric, offers us a powerful experience with death, honestly met and endured. Through her spoken commentary and a sensitive photo-essay, Mrs. Lund recreates her son Eric's five-year struggle against leukemia. As you view this filmstrip, keep these questions in mind:

1. What attitudes about death are presented here?
2. How are they similar or different from those we've discussed earlier?
3. How do the philosophy and values presented here speak to you and your own values?"

If time allows, spend some time discussing these questions at the conclusion of the filmstrip. If not, dismiss the group until the next meeting.

G. Handouts for Next Session

Give participants Information Sheet 2, "Death Ceremonies," and Information Sheet 3, "Philosophies of Death." Ask them to read both by next session.

Also hand out Information Sheet 4, "Bibliography of Readings." Just mention that this bibliography contains readings which they might find helpful if they wish to do further study.

Hand out "Workshop Outline." Say to the group: "This outline gives an overview of the aims of the workshop and the topics to be covered."

H. Topic for Next Session

Tell the participants that the topic for the next session will be "Customs Surrounding Death."

Death the Fulfillment of Life

INFORMATION SHEET 1

Songs about Death

"Mortality"
Composed by Daniel Reed
From the album: The New Golden Ring, "Five Days Singing," Vol. 2

Death, like an overflowing stream
Sweeps us away.
Our life's a dream,
An empty tale,
A morning flower
Cut down and withered in an hour.

"Ain't No Grave Can Hold My Body Down"
Sung by Joe Hickerson
Album: "Drive Dull Care Away," Vol. 1

Ain't no grave can hold my body down, my body down.
Ain't no grave can hold my body down, my body down.
When that first trumpet sounds,
I'll be gettin' up, and walkin' around.
Ain't no grave can hold my body down, my body down.

Well I've heard 'bout a place called heaven
Where the streets are paved with gold.
Well I never been to heaven
But, oh Lord, I've been told.
When I 'rive that throne of grace
I believe he'll 'point my soul a place
Ain't no grave can hold my body down, my body down.

"O Death, Where Is Thy Sting?"
From: "The Messiah" by G. F. Handel
By: London Symphony Orchestra and Chorus

O death, O death, where, where is thy sting?
O death, where is thy sting?
O grave, where is thy victory? O grave!
O death, O death, where, where is thy sting?
where, O grave, where is thy victory?
O death, where is thy sting?
O grave, O grave, where is thy victory?
O grave, where is thy victory?
The sting of death is sin,
the sting of death is sin,
and the strength of sin is the law,
the sting of death is sin, and the strength of sin
is the law.

"Bury Me Not on the Lone Prairie"
Sung by: Heddy West
Album: "Forty Great Folksongs" (Radio Shack)

Oh, bury me not, on the lone prairie.
These words came low, and mournfully.
From the pallid lips, of a youth who lay
On his dying couch, at the close of day.

He'd wasted his life, 'til around his brow
The shades of death, are a gathering now.
He'd thought of his home, and his dear friend nigh.
As the cowboys gathered, to see him die.

Oh, bury me not, on the lone prairie.
Where the wild coyotes, will howl o'er me.
Where the wild coyotes, and the winds sport free.
Bury me not, on the lone prairie.

I've often times wished, to be buried when I die,
In a little church yard, on a green hillside,
Close to my old home, there let me be.
Bury me not, on this lone prairie.

Little does it matter, so I've been told
A body's laid, when a heart goes cold.
Grant, grant as a boon to me.
Bury me not on the lone prairie.

His eyes they closed, and his voice fell there.
They'd taken no heed, to his dying prayer.
In a lonely grave just six by three,
They buried him there, on the lone prairie.

Oh bury me not, on the lone prairie.
These words come low, and mournfully.
From the pallid lips, of a youth who lay
On his dying couch, at the close of day.

"And When I Die"
By: Blood, Sweat, and Tears, Columbia Records

I'm not scared of dying,
And I don't really care.
If it's peace you find in dying,
Well, then let the time be near.

If it's peace you find in dying,
And if dying time is near,
Just bundle up my coffin,
Cause it's cold way down there.

(continued)

"And When I Die" (continued)

I hear that it's cold way down there.
Yeah, crazy cold way down there.
And when I die,
And when I'm gone,
There'll be one child born, in this world,
To carry on, To carry on.

Now troubles are many.
They're as deep as a well.
I can swear there ain't no heaven.
But I pray there ain't no hell.

Swear there ain't no heaven,
And I pray there ain't no hell.
But I'll never know by living,
Only by dying will tell.

Yes, only by dying will tell.
Yeah, only my dying will tell.

And when I die,
And when I'm gone,
There'll be one child born, in this world,
To carry on, To carry on. Yeah. Yeah.

Give me my freedom,
For as long as I be.
All I ask of living,
Is to have no chains on me.

All I ask of living,
Is to have no chains on me.
And all I ask of dying,
Is to go naturally.

Oh, I'm going to go naturally.
Here I go. Hay. Hay. Hay.
Here comes the devil.
Right behind.

Look out children!
Here he comes.
Here he comes. Hey.

Don't want to go by the devil.
Don't want to go by a demon.
Don't want to go by Satan.
Don't want to die uneasy.

Just let me go naturally.
And when I die,
And when I'm gone,
There'll be one child born, in a world,
To carry on, To carry on.
Yeah. Yeah.

Death the Fulfillment of Life

INFORMATION SHEET 2

DEATH CEREMONIES*

The Kotas

The Kotas are a people who live in seven small villages which are interspersed among the villages of their neighbors on a high plateau, the Nilgiri Hills, in South India. The height and inaccessibility of the plateau formerly isolated the tribal peoples who lived on it from the main currents of Indian civilization.

The Kotas observe two funeral ceremonies: the first, called the "Green Funeral," takes place shortly after a death and it is then that the body is cremated; the second, called the "Dry Funeral," is held once a year (or once in two years) for all the deaths that have occurred since the last Dry Funeral was celebrated. The terms are an analogy to a cut plant. At the first funeral, the loss is green and fresh in the mind; at the second, it is dried out, sere.

At the first funeral, a bit of skull bone is taken from the ashes of the pyre and reverently cached away until the second funeral. The Dry Funeral extends over eleven days and comes to a climax when each relic from the year's deaths is carried off to the cremation ground and, after complex ritual acts, the relics are recremated. The first funeral is attended by the close relatives and friends of the deceased. The second funeral is a grand occasion, attended by people from all the Kota villages and by non-Kotas as well.

The emphasis of the funeral ritual is much more on speeding the departure of the spirit from this world than it is on the "Motherland" beyond. Kotas are not much interested in the other world and have only sketchy ideas about it. They are quite precise about the purification which the spirit and the surviving kin must undergo in order that the spirit may depart for good.

Among the Kotas, as among many of the peoples of India, contact with death is considered to be deeply polluting. A polluted person is debarred from normal social relations until he has been purified by a proper and protracted ritual. The spirit of the dead person, too, is polluted in leaving the body, and the dual funeral rites purify the spirit so that it may take up proper relations in the afterworld.

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*From Mandelbaum, David G., "Social Uses of Funeral Rites." In Herman Feifel, The Meaning of Death. New York: McGraw-Hill Book Co., 1959.

Between the time of the body's last breath and the climactic end of the Dry Funeral, the lingering spirit is dangerous to men, especially to the deceased's closest kin. The climax comes when a pot is smashed, at the proper ritual juncture, in the cremation ground beyond the village. At that signal all who have attended the ceremony --that is to say, most of the villagers and many visitors--run back to the village without looking behind them. The living go one way, the dead another.

The Cocopas

The Cocopa, who lived mainly along what is now the Arizona-Sonora border, practiced some agriculture, but depended largely on hunting and gathering. Theirs was a relatively simple culture; they possessed few goods, they conducted few ceremonies. The whole tribe, in the late nineteenth century, consisted of some twelve hundred people, scattered in small settlements. People from several settlements might come together for a harvest fiesta, but many more would gather for the occasion of a mourning ceremony. The death ceremonies were the principal religious and social events of the tribe.

Soon after a death, the mourning members of the family became transported into an ecstasy of violent grief behavior. They cried, wailed, and screamed from the time of the death, without much interruption, for twenty-four hours or more until the body was cremated. The cremation ritual was directed mainly at inducting the spirit of the dead person to go on to the afterworld. To help persuade the spirit to depart, clothes, food, and equipment were destroyed so that the spirit could have these things in the hereafter.

Some time after the cremation, a Cocopa family would give a mourning ceremony to commemorate its dead. Then a large part of the tribe would gather, there would be speeches and lamentations for the dead. At all other times, the names of the dead could not be mentioned; at this mourning ceremony dead relatives were recalled publicly, summoned to mingle with the assembled tribesmen, and impersonated by men and women dressed in ceremonial costumes to resemble specific deceased persons. Presents were given to visitors, and valuable goods, including a ceremonial house and the ceremonial costumes, were burned for the benefit of the spirits.

The Hopi

The Hopi are one of the Pueblo tribes of Arizona. They are agriculturalists and follow a highly ritualized complex way of life. Funeral rites are held in the old tradition which minimizes the whole event of death and funerals.

The Hopi do not like the idea of death and they are afraid of the newly dead. Their funeral rites are small, private affairs, quickly over and best forgotten. Those who are bereaved may well feel the pain of loss as deeply as do mourners in any society, but they give

themselves over to no overt transport of grief of the kind expected of mourners among the Cocopa, Kotas, and in many another society. The Hopi cherish the middle way: they seek to avoid excess of any kind; their most desirable universe is one in which all is measured, deliberate, and under control. Weeping may be unavoidable, but it is not encouraged, for any cause. If one must weep--Hopi parents have told their children--it is best to weep alone, outside the village, where no one can see.

As soon as a death occurs in a family, the women of the household do lament; they cry a bit and speak of their loss. But there is no formal wailing nor is there a public gathering. The body is quickly prepared for burial and put into its grave as soon as possible. A woman relative washes the head; prayer feathers and a cotton mask are put on the corpse; it is wrapped and carried off straightway by the men of the household.

As with the Kotas and many other peoples of the world, contact with death brings pollution. Before persons who are thus polluted can resume normal relations with men and with the gods, they must divest themselves of the taint. Hence, on their return from the burying ground, the members of the household purify themselves ritually. The next morning a male relative of the deceased puts meal and prayer sticks on the new grave, prays for rain--a central good of Hopi life--and asks the spirit not to return to the village. To ensure the departure of the deceased, the relative symbolically closes the trail back to the village by drawing charcoal lines across it. When he comes back to the bereaved household, all wash their hair and purify themselves in pinon smoke. "They should then try to forget the deceased and continue with life as usual."

The spirit is believed to rise from the grave on the fourth morning and to follow the path to the land of the dead, somewhat in the general area of the Grand Canyon. It then becomes one of the great assembly of supernaturals. With these the Hopi are greatly concerned. The supernatural spirits are continually invoked; they are frequently asked for blessings; they come to the villages on ceremonial occasions. But the spirits are not Hopi; they are a different class of being and Hopi culture provides rules and means for dealing with them. The spirits are depersonalized entities; they do not have the characteristics of deceased friends and relatives. The Hopi go to great lengths to make sure that the dichotomy of quick and dead is sharp and clear. Many rites having to do with spirits conclude with a ritual device which breaks off contact between mortals and spirits.

Death the Fulfillment of Life

INFORMATION SHEET 3

Philosophies of Death*

Since death is inevitable, it would appear that individuals or groups will inevitably provide some meaning for death-related phenomena, since they will be forced, one way or another, to confront death. How they confront death and the set of definitions which are developed in this confrontation evidence considerable variation. The meaning of death which man has developed can be grouped into two broad orientations: a temporal, this-world orientation, and a spiritual or other-world orientation.

The temporal orientation to death involves the following:

1. Rejection or de-emphasis, in one form or another, of definitions of an afterlife. Man is viewed as a mortal being, living in an empirical world. "From dust thou art and unto dust thou shalt return" characterizes this type of orientation. Life and death are interpreted primarily in terms of their human or natural dimensions.

2. Belief in the finality of death. Death is seen as the end of the individual.

3. The concerns centered in death focus upon the consequences for the living--the bereaved or others.

4. The concerns of the individual with his own death tend to concentrate upon the present and the future. The future concern, however, is for the future of the living, not of the dead or dying.

5. The concern with immortality is not necessarily absent from such interpretations. Immortality is not defined in terms of the actual individual continuing indefinitely in some form or other, but rather on his influence, work, and projects being continued in the behavior and the culture of subsequent generations. Beliefs, behavior patterns, and money may be transmitted from one generation to another. The sins and blessings of the fathers may be visited upon the heads of their children from generation to generation, not in any mystical, supernatural manner, but rather through the process of cultural transmission. This interpretation is supported by the fact that members of a society are constantly being replaced, a few at a time, while the society continues indefinitely. Society is more than any one individual. It has an existence independent of the existence of any one individual. It is a group.

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*Vernon, G. The Sociology of Death. New York: Ronald Press, 1970, pp. 30-55.

The second orientation is called spiritual or otherworldly. A major characteristic of this orientation is that attention is directed away from the natural or temporal aspects of dying to nonnatural or maybe supernatural dimensions. Interpretations which involve such nonempirical concepts are not capable of being validated or invalidated by the scientific method, but are accepted by those who do endorse them as a matter of faith. A spiritual interpretation is characterized by the following:

1. Endorsement in one form or another of some type of afterlife or existence which continues beyond the physical or temporal death.

2. Rejection of the belief in the finality of death.

3. Concern with the temporal aspects of death coupled with and related to concerns with the spiritual aspect. Behavior may be directed toward a living audience, but also toward a supernatural audience.

4. The future-oriented concerns of man extend beyond the grave.

5. Concern is with immortality of the individual as some type of entity, with that concern being coupled to other concerns of a more temporal nature.

A combination of temporal and spiritual orientations is most likely woven into the meaning which most people have of death as well as into most funeral behavior.

Death the Fulfillment of Life

INFORMATION SHEET 4

BIBLIOGRAPHY

Alsop, Stewart. Stay of Execution: A Sort of Memoir. Philadelphia: Lippincott, 1973.*

A popular journalist's reaction when he discovered that he had leukemia and might soon die.

Aries, Philippe. Western Attitudes toward Death: From the Middle Ages to the Present. Baltimore: Johns Hopkins Press, 1974.*

A stimulating short work which utilizes literature, art, and other sources in order to chart changing attitudes toward death.

Becker, Ernest. The Denial of Death. New York: The Free Press, 1973.*

A fascinating and humane Pulitzer Prize winning work which argues that the fear of death is and has been a central factor in determining human conduct.

Brown, Norman. Life Against Death. Middleton, Conn.: Wesleyan University Press, 1973.*

Not an easy work to read but worth the effort. Brown argues that our fear of death and our desire for immortality contribute to neurosis and unhappiness.

Choron, Jacques. Modern Man and Mortality. New York: Macmillan, 1972.*

Concise and interesting coverage of concepts of death, death fears, and the implications of living. Remarkable in its wide and stimulating range of references and quotations.

De Beauvoir, Simone. A Very Easy Death. New York: Warner Paperback Library, 1973.*

An account of the dying process of this famous French writer's mother, along with the daughter's reflections on death and dying.

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*Available in paperback.

=Available in cassette books.

Feifel, Herman, ed. The Meaning of Death. New York: McGraw, 1959.*

An excellent anthology of nineteen selections encompassing religious, literary, philosophic, artistic, psychological, and medical approach to the subject.

Gatch, Milton McC. Death: Meaning and Mortality in Christian Thought and Contemporary Culture. New York: Seabury, 1969.

A historical approach which stresses approaches from the early Greeks to the Reformation.

Glaser, Barney and Strauss, Anselm. Awareness of Dying. Chicago: Aldine, 1968.

These two works deal with the interaction of families, hospital staff, and doctors with the dying.

Gordon, David. Overcoming the Fear of Death. New York: Macmillan, 1970.*

Simply written, this work discusses sources of the fear of death and offers a viewpoint for banishing this fear.

Grollman, Earl A., ed. Explaining Death to Children. Boston: Beacon, 1967.*

Ten selections from different perspectives, including psychological, religious, and literary.

Hinton, John. Dying. New York: Penguin, 1967.*

A physician discusses the taboo relative to death and the medical problems this causes, with recommendations for change. Comprehensible to the layman.

Kavanaugh, Robert. Facing Death. Freeport, N. Y.: Nash, 1973.*

Clearly written advice from a psychologist and former priest who has experienced the deaths of several people who were close to him, including his father.

Kubler-Ross, Elizabeth. On Death and Dying. New York: Macmillan, 1969.*

Simply and affectionately written, discusses this psychiatrist's work with dying patients in terms of "stages" of the dying process and her approach of helping by learning from the dying person.

Kutscher, Austin H., ed. Death and Bereavement. Springfield, Ill.: C. C. Thomas, 1969.

More than forty selections of all types, including some excellent literary treatment.

Lifton, Robert Jay and Olson, Eric. Living and Dying. New York: Praeger, 1974.*

A short, brilliant readable work. Lifton is a National Book Award winner for his Death in Life: Survivors of Hiroshima.

Maguire, Daniel C. Death by Choice. Garden City, N. Y.: Doubleday, 1974.

A Catholic theologian examines the moral implications of euthanasia.

Mitford, Jessica. The American Way of Death. New York: Simon & Schuster, 1963.*

A stinging criticism of the American funeral business.

Solzhenitsyn, Alexander. Cancer Ward. New York: Farrar, Straus & Giroux, 1969.*

The celebrated Russian novel that deals with life in the shadow of death.

Stannard, David, ed. Death in America. Philadelphia: University of Pennsylvania Press, 1975.*

Eight essays by cultural historians, anthropologists, literary scholars, and art historians.

Tolstoy, Leo. The Death of Ivan Ilyitch. Various editions.*

A superb fictional account of a middle-aged man face to face with a fatal sickness.

Vernon, G. The Sociology of Death. New York: Ronald, 1970.

A complete text covering meanings of death, bereavement, and disruptions of death upon social systems. It cites many studies and provides good summaries.

Death the Fulfillment of Life

SESSION II

Customs Surrounding Death

Aim:

To help participants:

(1) Recognize the universal human need for symbolic rituals in dealing with death.

(2) Understand some of the motives underlying cultural practices surrounding death in the United States.

(3) Understand that the customs and rituals surrounding death reveal an individual's or society's philosophy about death.

(4) Become more open in their willingness to discuss the topic of death through the sharing of feelings with other participants.

Resources Needed:

Newsprint, felt markers, and masking tape
Chalkboard, chalk, and eraser
Slides, "Funeral Customs Around the World"
Slide projector, screen
Cassette tape player
Lined tablets, pencils
List of questions on newsprint
Information Sheet 5, "Stages of Death and Dying"

Room Arrangement:

The room should be arranged with movable chairs placed in a semi-circle.
The slide projector, cassette tape player, and screen should be set up and ready for use.

Teaching Plans for Session: (5 minutes)

A. Introduction: Listing of "Death Customs" Activity

The session and the first activity might be introduced in the following manner:

"Much of what we believe and do in life is remembered, symbolized, and honored in the ways we end life and bury the dead. This is true for people throughout the world. Burial practices are common to all human groups. A comparative study of these practices and customs will help us increase our understanding of our own customs and our own need to express our feelings and concerns through ritual.

"By looking at the ways in which diverse cultures dispose of the dead, we can learn much about the goals and worth that life holds for those still living. In addition to what burial customs tell us about what is important to those who are alive, a study of death customs is important because it is a subject of universal interest and, yet, most of us know little about it. By comparing various practices associated with death, we can better understand the values and reasons behind the events surrounding the end of the life cycle.[1]

"Let's begin by examining some of the customs practiced in the United States. In small groups try to list as many customs surrounding death in the United States as you can in five (5) minutes."

B. Listing of "Death Customs" Activity (20 minutes)

Divide the participants into discussion groups of not more than six (6) members. Ask each group to select a recorder and a reporter. Have the assignment written on newsprint or chalkboard: "List as many customs surrounding death in the USA as you can in 5 minutes." Ask each group to list their customs on newsprint or chalkboard.

After the small group discussions, have each group, in turn, to report only one custom in order that each group will be able to make an input. Repeat the process until all the customs have been recorded. When the list is complete, tell the participants that "we will come back to this list after we have examined customs in other cultures, and we will try to draw some comparisons at that time."

C. Slides on "Funeral Customs Around the World"

Introduce the slides with remarks similar to these:

"You have read Information Sheet 2, 'Death Ceremonies,' which was handed out at the last session of the workshop. We would now like to view some slides on customs around the world. As you view the slides, keep in mind the following questions:

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[1]"Death a Part of Life," Center for Teaching International Relations, University of Denver, Denver, Colorado, p. i, 1976.

1. Which cultures are most similar in their customs? Which are most different? What explanations can you give for these similarities and differences?

2. What needs do people seem to have when a person dies?

3. What are the purposes of the ceremonies before the burial or cremation of the body?

4. Why do customs that serve the same function differ in so many ways?

5. What do these customs and rituals say about how persons view life and death?"

These questions should already be on newsprint and should be referred to as they are shared with the group.

View the slides.

D. Discussion of Slides (25 minutes)

Using the same small groups selected in activity B, have the groups to respond to the five (5) questions given prior to the filmstrip. Assign one question to each small group. If there are fewer than five groups, several groups would deal with more than one question. Work in the small groups about 10 minutes and then come together in a total group for a time of reporting and total group discussion of the ideas presented. The major idea should be recorded on newsprint or chalkboard.

E. Concluding Activity (20 minutes)

Return to the list, "American Customs Surrounding Death," recorded in Activity B. Ask the total group to discuss the questions: "How do our American customs serve the same needs as those practiced by other cultures? What purposes do they serve? What do our customs say about how we view life and death? Do any of our customs illustrate points of view similar to any of those found in Information Sheet 3, 'Philosophies of Death?' If so, which ones?"

F. Handouts for Next Session (5 minutes)

Give participants Information Sheet 5, "Stages of Death and Dying," and ask them to read it by next session.

G. Topic for Next Session

Tell the participants that the topic for next session will be "Stages of Death and Dying and Alternative Care."

Death the Fulfillment of Life

INFORMATION SHEET 5

The Stages of Death and Dying*

Dr. Elizabeth Kubler-Ross has observed five major stages in the dying process. Her studies have found that these stages tend to occur in order but not always. Below are her five stages and a brief description of each.

1. Denial and Isolation - This stage is evident when the persons becomes aware of his/her terminal illness and says, "No, not me." Periods of denial are used positively as a healthy way to cope with the shock of finding out the truth. This also causes many people to seek other advice about the seriousness of the illness. However, it is helpful for the patient to eventually reach a willingness to discuss the illness.

2. Anger - In this stage, the patient often asks, "Why me?" He/she feels resentment and envy, frustration and helplessness. They are angry with family, doctors, nurses, and friends, and need to feel cared for and respected.

3. Bargaining - After the anger subsides, the person begins bargaining with God, the staff or the illness itself. The person wants more time with which to be cured or to finish undone work. This stage is looked upon as a positive stage where the person is not giving up, rather fighting for what life is left.

4. Depression and Withdrawal - In this stage the person feels a great sense of loss either from past losses, disappointments and guilt or from future losses from family and material goods. Often the depression is not openly expressed, but should be allowed to proceed. Cheering up and supporting the person is very helpful during this stage. Dr. Kubler-Ross sees this stage of depression as necessary and beneficial if the patient is to die in a stage of acceptance.

5. Acceptance - In this final stage the person "contemplates the end with a certain degree of quiet expectation." The person is usually tired and weak, and is "resting before the long journey." It is a time when the person is more acceptant of death than family and friends.

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*Adapted from Elizabeth Kubler-Ross. On Death and Dying. New York: Macmillan, 1969.

Death the Fulfillment of Life

SESSION III

Stages of Death and Dying
and Alternative Care

Aim:

To help participants:

(1) Understand the various stages of the dying process and to understand that these stages are experienced by most people.

(2) Become aware of various caregivers involved in the dying process.

(3) Reflect on how alternative care systems might help in the acceptance of death.

Resources Needed:

Filmstrip projector, cassette recorder, and screen
Filmstrip and audiotape, "Toward an Acceptance"
Newsprint, felt markers or chalkboard, chalk, and erasers
Information Sheet 6, "Trigger Questions on the 'Stages of Death and Dying'"

Room Arrangement:

The room should be arranged with movable chairs placed in a semi-circle.
The slide projector, cassette recorder, and screen should be ready for viewing.

Teaching Plans for Sessions: (30 minutes)

A. Show the Filmstrip "Toward an Acceptance"

Introduce the filmstrip to the participants. The following statements might be used:

"In the last two sessions we have discussed our feelings about life and death and have become aware of the inter-relatedness of these dominant themes. Last session we specifically discussed the symbols and rituals of death and dying in various cultures, including our own. Perhaps we have come to a better understanding of how conceptions of life and death are translated and made real through our culturally rich traditions. Many of these traditions have a profound effect on how we face death--for ourselves, our friends, and loved ones.

"Death, as we all know, is not reserved only for older adults. Rather, we are confronted with the possibility of accident, disease or sudden death at any time in our lives. How we live with that possibility and react to its certainty have been the study of theologians, physicians, psychologists, sociologists, poets, and many other professional people.

"In this session we will discuss various stages that researchers have observed in terminally ill patients, and even those victims of accidents or sudden illness. How we as human beings deal with such a reality is a valuable topic for discussion and reflection.

"We are going to view a filmstrip based on the research of Elizabeth Kubler-Ross, a Physician/Psychiatrist at the University of Chicago. Her research articles, books, movies, and T.V. appearances have reached millions of people and have done much to remove the taboo nature of the study of death. Her major research has been focused on the major stages of death and dying. As you view the filmstrip, center your attention on these questions:

(1) What are the stages of death and dying?
(2) What is involved in each of the stages?
(3) What is the role of individuals who care (caretakers) for the dying person at each stage?"

B. Small Group Discussion of Filmstrip (20 minutes)

Following the filmstrip, divide the participants into five small groups. Assign one of Kubler-Ross' stages of dying to each group as follows: (1. Denial and Isolation, 2. Anger, 3. Bargaining, 4. Depression and Withdrawal, 5. Acceptance.) Hand out Information Sheet 6, "'Trigger Questions' on the Stages of Death and Dying."

C. Total Group Discussion (30 minutes)

Return to the total group and have each small group to report its thoughts. Allow some time for total group discussion after each group reports. Questions such as these might guide the discussion:

How do you react to these thoughts?
Are there other insights which come to you regarding these ideas?

D. Alternative Care Systems (20 minutes)

Continue in a total group discussion, but shift the group from its previous thoughts to the present topic by using words similar to these:

"We've been looking at the stages of death and dying and we've been looking at some of the needs the individual has at each stage. We've also given some thought as to the kind of roles caregivers need to fulfill at each stage. Given this background, let's spend a few moments brainstorming about some alternative care systems which may more realistically take into account the stages of death and the particular needs of the individual at each stage. First of all, how can better care be provided for the dying person at each stage?"

Try to get the group to quickly list a number of ways that care can be provided. You might record these ideas on newsprint or chalkboard. Do not spend much time on each idea. Just get as many ideas as possible.

After a few minutes of brainstorming, ask the group to discuss these questions:

(1) In what ways do you think professional caregivers could become well-trained and more sensitive to the needs of dying persons? Can persons like us be trained and become more sensitive caregivers? How?

(2) Can some of the fears and anxieties of the death experience be lessened through the efforts of caregivers--both professional and lay persons? Why or why not?

E. Topic for Next Session

Tell the participants that the topic for the next session will be "Handling Grief."

Death the Fulfillment of Life

INFORMATION SHEET 6

"Trigger Questions" on the Stages of Death and Dying

DENIAL AND ISOLATION

1. When do people become aware that they are dying?
2. What is the best way to inform the person?
3. Who is responsible for informing the person--the doctor, the family, a minister?
4. What clues are usually present in a terminal situation--physical dysfunction, visitors' emotions, demeanor of the staff?
5. How does conflict between the doctor's drive for life and the reality of death help or hinder the awareness process?
6. How is denial a protective device?
7. How does denial prolong the process of acceptance?
8. What caregiver roles are needed by the dying person at this stage?

ANGER

1. How do the anger and resentment of becoming aware of death fit into a normal process of the death experience? For young people? For older people?
2. What are the conflicts between sudden illness versus long terminal decline? Is it fate or natural order?
3. Which caregivers are involved in helping the patient use this stage positively?
4. What caregiver roles are needed by the dying person at this stage?

BARGAINING

1. Does the struggle excited by death awareness block suggestions for improvement or drive the patient to seek cures elsewhere?
2. Should the patient be given any alternative activities or life purposes which could possibly enhance positive feelings about the rest of one's life, e.g., travel, community involvement, creative outlets?
3. Do people believe that time cures all ills?
4. What caregiver roles are needed by the dying person at this stage?

DEPRESSION AND WITHDRAWAL

1. How can people be supportive of a person who feels sad about dying?
2. How can people avoid or overcome feelings of pity and grief to become a stronger, more sensitive friend to the dying?
3. How are nonverbal signals shared (nods, smiles, holding hands)?
4. What caregiver roles are needed by the dying person at this stage?

ACCEPTANCE

1. What is the relationship between acceptance and one's philosophy of life?
2. Is acceptance related to satisfaction with life?
3. How does acceptance help the person go about preparing for death?
4. What are some ways of alleviating the fear of death?
5. What caregiver roles are needed by the dying person at this stage?

Death the Fulfillment of Life

SESSION IV

Handling Grief

Aim:

To help participants:

(1) Understand the meaning of grief.

(2) Understand the stages of grief.

(3) Examine their own feelings about grief.

(4) Become aware of roles that caregivers may assume with those in grief.

Resources Needed:

Tapeplayer
Definition of grief on newsprint
Newsprint and felt markers or chalkboard and chalk
Information Sheet 7, "Lament" and audiotape
Information Sheet 8, "Grief Work"
Information Sheet 9, "How to Be a Caregiver in a Grief Situation"
Information Sheet 10, "Prayer of St. Francis", and audiotape
Booklet "On Being Alone," published by American Association of Retired Persons
Leaflet, "Bereavement--A Family Crisis"

Room Arrangement:

The room should be arranged with movable chairs placed in a semi-circle.

Teaching Plans for the Session:

A. "Lament" Tape (10 minutes)

Begin the session in some way similar to this:

"In our last session, we spent some time looking at the stages of death and dying. These were the stages the dying person goes through, but there is another concern in the dying process which was not really dealt with last time. I am talking about the grief experienced by those persons left behind. The healthy handling of grief is a real concern, and it's what we will be dealing with in this session. To start off our thinking about grief, I would like for us

to listen to a poem by Edna St. Vincent Millay entitled Lament. As you listen to this poem, try to sense what it means to grieve."

Give the participants Information Sheet 7, "Lament," and play the tape.

After the tape, ask the participants to describe what grief is as they sensed it in this poem. Do not take a long time with these descriptions. Just quickly get a number of ideas from the group members.

B. Triads (15 minutes)

Divide the participants into groups of three (3). Ask each person to briefly tell their group some grief experience they have experienced, and in one word try to describe how they felt. Take about 5 minutes in the triads and then let the groups share their "one-word descriptions" with the total group. Record these words on newsprint or chalkboard. Leave these words before the group for the duration of the session as a "mood-setter" or "conscious-raising experience."

C. Define "Grief" (10 minutes)

In an effort to come to some understanding of what is meant by "grief," spend a few moments in getting the group members to express how they would define "grief." You could introduce this activity by saying:

"We have been describing what grief is like and how we feel, but how would you define 'grief'?"

Let several group members share their understanding of grief, and then share this definition with the total group:

"Grief is the human reaction to loss, specifically the loss of someone by death. It is among the deepest pains experienced by a person."

Show the definition on newsprint. Ask the group, "How do you react to this definition? How would you change it?" Again, a large amount of time does not need to be spent on this activity. The main purpose of this activity is to get the individuals to voice their ideas of what "grief" is and to come to some general understanding of what they as a group mean when they speak of "grief."

D. Study of "Grief-Work" (30 minutes)

Introduce the next activity in the following way:

"'Grief-work' is a term used first by Sigmund Freud in which he emphasized the need of completing the task of mourning, to accept the reality of the death of a loved one, and to go through the process of cutting the emotional ties with the dead person. It is hard work, and usually takes considerable time, but on its completion a person becomes gradually able to seek fresh attachments in a free and uninhibited manner. Otherwise the person carries unresolved grief which can show up in various illnesses in the years to come. We want to spend a little time on seeing if we can understand how persons can work through grief in a healthy fashion. Get back into your triads and spend about 30 minutes discussing the questions at the end of Information Sheet 8, "Grief Work."

E. Total Group Discussion (20 minutes)

Return to the total group and discuss the four (4) questions just discussed in the triads. Each triad does not have to "report." Ask each of the following questions and let various persons respond as they will.

(1) How realistic do you feel the "Three Stages of Grief" and/or the "Ten Stages of Good Grief" are? Explain.
(2) Does one have to go through either the "Three Stages" or "Ten Stages" to be healthy? Explain.
(3) Do you see the "Three Stages" and/or "Ten Stages" in the Jewish Ritual of Mourning? Where? What's missing?
(4) Can other persons (caregivers) help in the grieving process? Why or why not?

F. How to Be a Caregiver (20 minutes)

The discussion of question No. 4 will be a natural "lead in" for the next activity. Introduce this portion of the session by saying:

"We often feel inadequate in a grief experience. We don't know what to do or we just can't seem to find words to express how we feel or to bring comfort to the bereaved. Let's examine a list of 'Aids for the Caregiver'."

Distribute Information Sheet 9, "How to Be a Caregiver in a Grief Situation."

Use these questions in the discussion:

(1) How realistic are these "aids"?
(2) Should any be omitted? Why?
(3) What other "aids" should be added? Why?

G. Prayer of St. Francis

Hand out Information Sheet 10, "Prayer of St. Francis."

Close the session by playing the tape, "Prayer of St. Francis." Introduce the tape by saying:

"There is a famous prayer attributed to St. Francis of Assisi which could very easily be the motto of a caregiver. Listen closely to his words. You can follow the words on Information Sheet 10."

H. Hand Out Publication "On Being Alone"

"This publication is provided to you by the American Association of Retired Persons hoping that it may bring comfort to you or to a friend."

I. Handout leaflet "Bereavement--A Family Crisis"

J. Topic for Next Session

Tell the participants that the topic for the next session will be "Choices About Life and Death."

Death the Fulfillment of Life

INFORMATION SHEET 7

Lament

Listen, children:
Your father is dead.
From his old coats
I'll make you little jackets,
I'll make you little trousers
From his old pants.
There'll be in his pockets
Things he used to put there,
Keys and pennies
Covered with tobacco;
Dan shall have the pennies
To save in his bank;
Anne shall have the keys
To make a pretty noise with.
Life must go on,
Though good men die;
Anne, eat your breakfast;
Dan, take your medicine;
Life must go on:
I forget just why.

Edna St. Vincent Millay

Death the Fulfillment of Life

INFORMATION SHEET 8

Grief-Work

The Three Stages of Grief

I. The Initial Stage of Grief:
Shock, disbelief, numbness, daze, anguish, unreality

II. The Second Stage of Grief:
Acute grief, suffering, erratic moods, guilt, anger, anxiety, depression, withdrawal, irritability, restlessness, loneliness, sadness, pain, ambivalance, hallucinations, weeping, despair

III. The Third Stage of Grief:
Beginning Recovery. A slow returning to life, new creative activity, new interests, satisfactions, ups and downs, regressions, finally recovery.

Many counselors believe that the grief process will take at least a year, for some more people more. The first stage usually lasts a few days, the second stage six months or so, and the third stage, an additional six months.

Granger Westberg's Ten Stages of Good Grief
Stage One - We are in a state of shock.
Stage Two - We express emotion.
Stage Three - We feel depressed and very lonely.
Stage Four - We may experience physical symptoms of distress.
Stage Five - We may become panicky.
Stage Six - We feel a sense of guilt about the loss.
Stage Seven - We are filled with hostility and resentment.
Stage Eight - We are unable to return to usual activities.
Stage Nine - Gradually hope comes through.
Stage Ten - We struggle to readjust to reality.

JEWISH RITUALS OF MOURNING

1. From the time of death until the funeral the survivors are left to themselves. All external matters are taken care of for them by others--food is provided, the house is taken care of, business is closed. One does not comfort them yet--they are considered to be in shock and should be left to their grief.

2. The funeral is important. Psalms are read--they say what we want to say and can't, and they have a special magic anyhow. A eulogy is mandatory, with rare exceptions. There is a mourner's prayer.

At the cemetery, the ritual is brief. After burial--which is completed while everyone is present, and usually with everyone participating--family and friends form parallel lines facing in, and the mourners walk between the lines and people say the formula: "May God comfort you together with all the mourners of Zion and Jerusalem."

3. "Shiva" is observed. The word means "seven," but it rarely involves seven full days. During Shiva, the family remains at home, and friends come to visit. Ideally, they all sit together and talk. In practice, there is lots of food and, by the end of the week, some gaiety.

4. "Shloshim" is observed. This means "thirty," and it lasts for a month after the death. Then the men go back to work, the children go back to school, the women go about their various occupations. There are no social gatherings or parties, but all routines are carried on during this period.

5. For eleven months after the death, designated people (close relatives) go to the synagogue a stated number of times a week and during the service say the Kaddish, the mourner's prayer.

6. Each year after that, in perpetuity, on the anniversary of the death, the designated people go to the synagogue and recite the Kaddish during services.

7. On stated occasions during the year there is a Yizkor, a memorial service for all deceased, and the Kaddish is said by all the designated people.*

For a fuller exposition of the Jewish concepts of Dying and Mourning, see Elizabeth Kubler-Ross, Death, the Final Stage of Growth, Chapter 3, pp. 38-51.

QUESTIONS

1. How realistic do you feel the "Three Stages of Grief" and/or the "Ten Stages of Good Grief" are? Explain.

2. Does one have to go through either the "Three Stages" or "Ten Stages" to be healthy? Explain.

3. Do you see the "Three Stages" and/or "Ten Stages" in the Jewish Ritual of Mourning? Where? What's missing?

4. Can other persons (caregivers) help in the grieving process? Why or why not?

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*Copied. Morris, Sarah. Grief and How to Live with It. New York: Grosset and Dunlap, 1972.

Death the Fulfillment of Life

INFORMATION SHEET 9

How to Be a Caregiver in a Grief Situation

Blessed are they that mourn, for they shall be comforted. Matthew 5:4.

"For sorrow shared is sorrow diminished."

"When death destroys an important relationship, it is essential that someone be found partially capable of replacing that relationship." Joshus Liebman

Aids for the Caregiver

One very important step toward being a caregiver is your attendance in this course and what you have learned and are learning.

1. Be informed; try to understand the grief process.
2. Be there; go to your friend or loved one.
3. Let the bereaved set the pace--to talk or to be quiet.
4. Learn to listen: creatively, nonjudgmentally, interestedly.
   Listen to what I am saying; that is all the comfort I ask from you. (Job 21:1-2 TEC)
   a. Listen with the "third ear"--it brings comfort and healing
   b. Listen to angers and hurts
   c. Listen to failures and alienations
5. Include the bereaved in your activities.
6. Be supportive in the ups and downs of the bereaved.

Death the Fulfillment of Life

INFORMATION SHEET 10

"Prayer of Saint Francis"*

LORD,
    Make me an instrument of your health:
where there is sickness,
    let me bring cure,
where there is injury,
    aid;
where there is suffering,
    ease;
where there is sadness,
    comfort;
where there is despair,
    hope;
where there is death,
    acceptance and peace.

GRANT that I may not:
so much seek to be justified,
    as to console;
to be obeyed,
    as to understand;
to be honored,
    as to love....
for it is in giving ourselves
    that we heal,
it is in listening,
    that we comfort,
and in dying
    that we are born to eternal life.

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*Copied from Kubler-Ross, E. Death, the Final Stage of Growth. Englewood Cliffs, N. J.: Prentice Hall, 1975.

Death the Fulfillment of Life

SESSION V

Choices about Life and Death

Aim:

To help participants:

(1) Understand their choices in determining how, when and where they wish to spend their last days or years.

(2) Examine their own attitudes and feelings about euthanasia.

(3) Become familiar with the "Dying Person's Bill of Rights" and the "Living Will."

(4) Become familiar with the hospice movement and its development.

Resources Needed:

Video tape "A Dose of Reality"
Video player and monitor
Information Sheet 11, "Case Study"
Information Sheet 12, "The Dying Person's Bill of Rights"
Information Sheet 13, "The Living Will"
Information Sheet 14, "Living to the End"
Leaflet, "Hospice of North Carolina, Inc."
Chalkboard or newsprint
Leaflet, "Have You Made Your Will?"

Room Arrangement:

The room should be arranged with movable chairs placed in a semi-circle.
Video player and monitor should be set up and ready for use.

Teaching Plans for Session:

A. Introduction: Euthanasia (5 minutes)

The session may be introduced in the following manner:

"In this session we will examine the choices we may or may not have regarding how, when and where we may wish to spend our last days or years.

"Many of us are familiar with the Karen Quinlan case. Karen was a 21-year-old girl from New Jersey whose parents requested

that the respirator be removed after she had spent six months on the machine in what her doctors called a 'persistent vegetative state,' so that she could be allowed to die 'with grace and dignity.' The doctors denied their request, and a long legal battle finally ended in a decision to remove the machine. As of April 1979 she has been in a nursing home and existing without the use of artificial devices. This case caused the American public to re-examine its stand on euthanasia.

"The term euthanasia means 'a good death,' and is derived from the Greek words 'eu' (good) and 'thantos' (death). The generally accepted definition for active euthanasia is painlessly putting to death persons who have incurable, painful, or distressing diseases or handicaps. It is sometimes called 'mercy killing,' and is illegal. Passive euthanasia means the doctor stops treating the patient and allows him/her to die, and this practice is legal. The Euthanasia Society advocates that there is a right to die and recommends having voluntary, passive euthanasia. 'Voluntary' means it's done with the patient's consent. 'Passive' means the physician simply stops treating the patient and allows him/her to die. To the Society, a good death is one without pain, lingering or medical heroics; one with dignity, honesty, and compassion.

"The case of Karen Quinlan raised the delicate medical and legal issue of: whether in addition to the right to live there is, in certain circumstances, a right to die. Therefore, some questions which we might explore are: (1) Do I have a choice in deciding when I will accept extraordinary medical help? (2) Can I decide where and how I will die?"

B. Case Study (25 minutes)

Divide participants into discussion groups of not more than six (6) members. Ask each group to select a recorder and a reporter.

Hand out "Case Study" (Information Sheet 11). Ask participants to read the case study and discuss the questions at the bottom of the sheet.

After the small group discussions ask the reporter for each group to report on conclusions reached by the group.

C. "The Dying Person's Bill of Rights" (10 minutes)

Ask participants to re-assemble in larger group.

The Dying Person's Bill of Rights may be introduced as follows:

"Recently a document was developed at a workshop on 'The Terminally Ill Patient and the Helping Person' at Lansing, Michigan. The document is called 'The Dying Person's Bill of Rights.' It is not a legal document but it offers some guidance to families of the terminally ill."

Distribute copies of "The Dying Person's Bill of Rights" (Information Sheet 12) to participants. Ask participants to follow as leader reads "Bill of Rights" and keep the following questions in mind as they read:

(1) Do you agree or disagree that dying persons should have these rights?
(2) Which items would you omit or add to the list? Why?

Following the reading ask participants to respond to the two questions.

D. The Living Will (10 minutes)

The living will may be introduced as follows:

"Another document called the 'Living Will' has been developed by the Euthanasia Society. This will provides a way for allowing the individual to have his own wishes be considered as well as to provide legal protection for the doctors and nurses. It is also designed to avoid leaving survivors with a sense of guilt. There is widespread and increasing acceptance of this idea, and this practice of 'euthanasia' by advance agreement of the family, patient, and doctor allows one to die in dignity and not be kept 'alive' with extraordinary measures which prevent 'nature from taking its course.' It should be remembered that this is simply a choice--one choice, and that this will may be revised, ignored, or accepted--It may be revoked at any time simply by verbally stating to the doctor that you have changed your mind--It is more a moral commitment than a legal document."

Hand out "Living Will" (Information Sheet 13) and ask participants to follow as leader reads "will."

Ask participants the following questions: Could the "Living Will" ease the trauma of a death in a family? How? Would this will be useful to you? Why? Why not?

E. The Hospice Movement (10 minutes)

The hospice movement may be introduced as follows:

"No discussion of conditions surrounding the death experience would be complete without some reference to the hospice movement. As a program, it is gaining great momentum throughout the country and certainly deserves our attention.

"The hospice movement may be a choice which makes the thought of euthanasia unnecessary. The word hospice means 'a community of sojourners along the way.' In the Middle Ages, a hospice provided a resting place for weary travelers. Today, hospice care provides the same kind of comfort for one who is near the end of life's journey, as well as support for the families preparing for the eventual death of a family member.

"Dr. Cicily Saunders established the first hospice in London in the late 1960s, and its success has provided the impetus for the movement in the United States, where New Haven, Connecticut, is the location of the National organization. There are presently many hospice organizations in the United States in various stages of development. The North Carolina Hospice was formed in 1977, with Winston-Salem established as the state headquarters.*

"The hospice philosophy is as follows: The philosophy of hospice care is not radically different from that which has always been espoused by conscientious physicians as the ideal for humane medical care of persons. But there is a difference in emphasis: when cure of the disease in a particular person is no longer the appropriate goal (because no longer possible), then care becomes the appropriate goal. Hospice has to do with enabling a person to live (as distinct from 'exist') until he dies. This is a program of care that pays serious attention to symptoms--that relieves pain . . . and supports the family system.**

"With this background, perhaps the video tape we are going to see will provide additional insight into caregiving. This film portrays a philosophy similar to that of the hospice."

As you view the video tape think about the following questions (write questions on board or newsprint):

(1) How did this experience meet the needs of the persons in the film?

(2) Does hospice provide a better way of dying? Why or why not?

(3) Was the person's own wishes and her best welfare always maintained?

(4) What was the role of the caregivers?

F. Show Video Tape: "A Dose of Reality" (15 minutes)

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*Hospice of North Carolina, Inc.

**Ibid.

G. Discussion (15 minutes)

Following the video tape ask small groups to re-assemble and select a new recorder and reporter. Ask each group to discuss one of the four questions. Each small group should report back to the total group following discussion.

H. Small Group Reports (10 minutes)

I. Hand Out Information Sheet 14, "Living to the End," and the Leaflets, "Hospice of North Carolina, Inc." and "Have You Made Your Will?".

Ask participants to take home information sheets for further reading.

J. Topic for Next Session

Tell the participants that the topic for the next session will be "Decisions in Life about Death."

Death the Fulfillment of Life

INFORMATION SHEET 11

Case Study

Mrs. Smith is a seventy-six-year-old widow. One evening she was found collapsed in her bathroom. She was rushed by ambulance to the hospital. The emergency room doctor could not feel her pulse nor obtain her blood pressure. She was in a deep coma.

The doctor immediately began mouth-to-mouth resuscitation and later a nurse continued with a hand-operated bag ventilator. The EKG monitor showed only a rapid heart rate, and no evidence of a heart attack. A continuous intraveneous drip had been started, containing the standard scientifically correct drugs. Soon a stronger heartbeat could be heard and a pulse could be felt. She still remained in a deep coma and did not react to strong stimuli.

Meanwhile, her daughter was called and told of her mother's critical situation. She said: "Do everything you can."

As Mrs. Smith's breathing became labored, a breathing machine was used to sustain breathing. In spite of these efforts, the coma deepened. An hour later, a neurosurgeon decided to take X-rays of the blood vessels to her brain and found that she had suffered a hemorrhage due to the rupture of one of the blood vessels of the brain. The surgeon then performed surgery to stop the bleeding. The surgery was successful, but Mrs. Smith remained comatose. She was transferred to intensive care where she remained for 10 days receiving all the support measures possible. By the end of this time, her coma lightened slightly. She moved when she felt pain. She then developed another abnormal rapid heart rhythm. Electrical shock was used and a normal heart beat was restored.

After 10 days she was transferred to a regular hospital room, but further improvement was slow and limited. She would respond to simple questions but could not express herself. She could not feed herself and was finally discharged to a nursing home 4 weeks after arriving at the emergency room.

Question:
Do you feel comfortable with the efforts made to prolong Mrs. Smith's life? If so, why? If not, why not?

Death the Fulfillment of Life

INFORMATION SHEET 12

The Dying Person's Bill of Rights

I have the right to be treated as a living human being until I die.

I have the right to maintain a sense of hopefulness however changing its focus may be.

I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.

I have the right to express my feelings and emotions about my approaching death in my own way.

I have the right to participate in decisions concerning my care.

I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.

I have the right not to die alone.

I have the right to be free from pain.

I have the right to have my questions answered honestly.

I have the right not to be deceived.

I have the right to have help from and for my family in accepting my death.

I have the right to die in peace and dignity.

I have the right to retain my individuality and not be judged for my decisions which may be contrary to beliefs of others.

I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.

I have the right to expect that the sanctity of the human body will be respected after death.

I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

This Bill of Rights was created at a workshop on "The Terminally Ill Patient and the Helping Person" in Lansing, Michigan, sponsored by the Southwestern Michigan Inservice Education Council and conducted by Amelia Barbus.

Death the Fulfillment of Life

INFORMATION SHEET 13

The Living Will

TO MY FAMILY, MY PHYSICIAN, MY LAWYER, MY CLERGYMAN
TO ANY MEDICAL FACILITY IN WHOSE CARE I HAPPEN TO BE
TO ANY INDIVIDUAL WHO MAY BECOME RESPONSIBLE FOR MY HEALTH, WELFARE OR AFFAIRS

Death is as much a reality as birth, growth, maturity and old age--it is the one certainty of life. If the time comes when I, _____, can no longer take part in decisions for my own future, let this statement stand as an expression of my wishes, while I am still of sound mind.

If the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or "heroic measures." I do not fear death itself as much as the indignities of deterioration, dependence and hopeless pain. I therefore ask that medication be mercifully administered to me to alleviate suffering even though this may hasten the moment of death.

This request is made after careful consideration. I hope you who care for me will feel morally bound to follow its mandate. I recognize that this appears to place a heavy responsibility upon you, but it is with the intention of relieving you of such responsibility and of placing it upon myself in accordance with my strong convictions that this statement is made.

Signed _____

Date _____

Witness _____

Witness _____

Copies of this request have been given to _____

_____

_____

_____

For additional information contact:
Euthanasia Education Fund
250 West 57th St.
New York, New York

Death the Fulfillment of Life

INFORMATION SHEET 14

"Living to the End"*

By John Knoble

Some Connecticut Yankees have imported from England a revolutionary medical concept that promises liberation from one of humanity's oldest fears--the drug-deadened, death-in-life long considered inevitable for the patient with a chronic degenerative disease. Known as the hospice movement, it makes the thought of euthanasia unnecessary.

The hospice movement (the word "hospice" means a community of sojourners along the way) says the time has come for medical science to apply its wisdom to the task of helping people who can't get well die comfortably and meaningfully. It seeks to do this by establishing specialized terminal-care facilities where patients may live until they die. Over 50 groups have been formed in the U.S.A.

Interest in the concept was sparked in 1969 when the Rev. Edward F. Dobihal Jr., director of the Department of Religious Ministries at Yale-New Haven Hospital, spent several months as visiting chaplain at St. Christopher's Hospice in northeast London, founded in 1949 by Dr. Cicely Saunders.

Chaplain Dobihal had seen countless people go through the dying process in the hectic atmosphere of a general hospital and he was impressed with the difference at St. Christopher's. He began to talk with his Yale Medical School and School of Nursing associates. A group visited St. Christopher's and was impressed.

A young expert in pain control, Dr. Sylvia Lack, came to New Haven in 1973 to initiate the Home Care Program. She had worked for two years in a joint appointment at St. Joseph's Hospice and St. Christopher's. In her work she uses combinations of drugs instead of just one, with excellent results, and stresses that "non-narcotic drugs can be used for a long time effectively when psychological factors affecting the patient are positive."

Financed by the National Cancer Institute, Hospice, Inc. has completed the second full year of its Home Care Program. Now, foundations and individuals have contributed to the goal of building a $3.1 million, 44-bed inpatient facility in Branford, Conn. A $1.5 million

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*Reprinted by permission from Modern Maturity, August-September 1977, pp. 63-64.

Federal appropriation was approved by the House Subcommittee on Labor and Health, Education and Welfare this May. A National Advisory Council headed by Elisabeth Kubler-Ross (author of the best-selling "On Death and Dying") includes more than 50 physicians and nurses, all recognized across the country for their expertise in terminal care.

The Branford inpatient facility was inspired by what has been done in hospices in England. It is designed by a group of New Haven concerned citizens, including doctors and nurses, as a model for American hospices. The group has already shown how well the concept works in the Home Care Program. Money for the facility is being sought from small as well as large contributors; it is for everyone.

Only a score of American general hospitals now have terminal-care departments that provide medical resources for comfort beyond the scope of nursing homes or convalescent hospitals.

To date, the Home Care Program has served some several hundred terminal patients and their families. In one recent 12-month period, 50 out of 170 patients died; of these, 17--23 percent more than the national average percentage--died at home. Although the numbers are too few to make a statistical point, hospice people consider this a direct experience confirmation of similar percentages over the years in English hospices. And the figures provide grounds for their own confidence that hospice-type home care will enable many more people to have this universal wish granted.

Drugs are administered orally before the onset of pain. The procedures are used that have been found effective in England. "No one ever has to cry out for relief," Chaplain Dobihal promises.

A hospice report also showed that those who did die in a hospital had been able to stay home an average of approximately two weeks longer before entering.

The daughter of one patient wrote: "My mother, ill with cancer, wished to stay at home with her family. I needed help. Her physician recommended hospice. It was very reassuring to know that we could get help at any time, day or night. They always came to the house daily. In fact, they offered to come and stay with mother all night so I could get some sleep. At the time of her death they were here with us. It's been two months since her death, and they are still in touch with us."

By means of a sophisticated combination of anti-emetics, individual formulas are found for each patient for control of nausea, so that patients have an appetite for eating. "A simple meal is a powerful symbol of life," Nurse Charlotte Gray of the Yale School of Nursing says.

Hospice people do not like the term often applied to hospices--"a beautiful place to die." The focus, they insist, is on life. "Most patients will be able to engage in meaningful conversation right up to the day of taking leave," is a familiar prediction by hospice enthusiasts. In the new building, children will be welcome visitors.

Not long ago, my wife and I decided to see St. Christopher's for ourselves. We found a building more like a vacation lodge than a hospital. "Ministering to the whole person is so important in pain control," Dr. Saunders says. "And that has many facets. It starts with the morale of the staff and the volunteers who go into the community. It includes relations with the patient's primary physician." She mentions how spiritual well-being is furthered by the help of clergy, psychologists, and other professionals, as well as by the constant evidence that those who surround the patient care.

Nurse Barbara McNulty of St. Christopher's told us: "Six patients who recently came into residence have been released to their homes. We have actually found that there is a good chance in many cases that our methods may prolong life."

The Branford Hospice will copy St. Christopher's provision for a nursery for children of staff members, "so they won't have to worry about their youngsters, and so the sound of children's feet and voices will witness to life."

Dr. Saunders, however, insists that St. Christopher's should not be thought of as a model for Branford's Hospice. "You in America have your own distinctive genius," she says.

Lo-Yi Chan, the architect of Branford's Hospice, talks about the facility: "Color, furnishings, and space will convey the impression that this is a pleasant place to be. Whether in a wheelchair or a bed, the patient will be mobile. In good weather, patients' beds can be moved into a garden."

While technical support systems will be at a minimum as compared to a general hospital, palliative X-ray, pharmacy, diagnostic radiology, oxygen, and suction systems will still be used as needed, with a back-up arrangement for quick transportation to a general hospital if other supports are prescribed.

"The Hospice will look like a part of life," Chan says. "Windows make it possible for a world outside to come inside. The setting must invite a nurse to sit on a bed with a patient, maybe hold a hand or shed a sympathetic tear. There will be places for serenity, for when one comes to visit one's father he may find something to say if the room is designed so they are truly alone."

The cost of care in the residential facility will be more than most nursing homes, but considerably less than in a general hospital; it is estimated at 50 percent less. The fact that the Hospice Program of Home Care reduces the number of days necessary for hospitalization makes for additional saving.

As the hospice movement grows, more and more beds will be freed in acute-disease hospitals throughout the country for care of patients who can possibly recover.

Chaplain Dobihal says: "In the hospice program, patients, family and staff share in the care-giving process. Patients provide other patients with inspiration and encouragement, giving them a sense of service when they might otherwise feel they are of no further use to anyone.

"They enable us to surmount the denial of death we have been taught--denial that has allowed us to tolerate the inhuman vegetation that is the hallmark of superfluousness among the terminally ill in America. But there are no superfluous people, and the extent to which we can humanize the process of dying--by consecrating death as a part of life--is a measure of our ability to humanize the process of living."

Death the Fulfillment of Life

SESSION VI

Decisions in Life about Death

Aim:

To help participants:

(1) Become more aware of many of the details involved in the dying process: estate planning, funeral arrangements and family affairs.

(2) Understand that through a fulfillment of life, death can become a fulfilling experience.

(3) Reach a closure between their past and present feelings about death and facilitate plans for the future.

Resources Needed:

Newsprint, felt markers and masking tape
Information Sheet 15, "Some Practical Hints about Death Arrangements"
Pencils
Information Sheet 16, "Quotations about Death"
Package of posttest questionnaires
Booklet, "A Manual of Death Education"

Room Arrangement:

The room should be arranged with movable chairs placed in a semicircle.

Teaching Plans for Session:

A. Introduction to the Discussion of Death Arrangements (45 minutes)

This final session and the first activity might be introduced in the following manner:

"In the five previous sessions we have explored our feelings about death--cultural influences on American views of dying, the stages of dying, the process of grief, and the choices many individuals have about how they will die. In this final session, we will focus on other kinds of important choices people make throughout their lives. A source for much anxiety and uneasiness about death is the whole notion of

death arrangements. How well have I taken care of my financial obligations? Have I provided well for my family? What kind of funeral arrangements do I want? How can I ease the burden on my survivors? These questions and many others are important problems in the death experience, and we are going to try and answer some of them as well as explore others of concern to you."

Divide the participants into groups of not more than six persons. Have half of the groups to list as many practical and legal activities as possible that should be taken care of when planning one's estate. Ask them to put their lists on newsprint. Have the other half of the groups to list as many activities as possible that should be taken care of when planning one's funeral. Ask them to place their lists on newsprints.

After 10 minutes, have the groups to place their lists side by side before the total group. Have the lists relating to estate planning placed together and have the lists relating to funerals together. Starting with the estate lists, begin reading and mark out the duplications between the lists, and compile one final list of things to be taken care of when planning one's estate. Use the same process to compile a list of activities related to planning one's funeral.

Hand out Information Sheet 15 and ask the group to compare the handout with the compiled lists for any similarities and differences between the groups. Looking at the compiled lists, suggest to the participants that they add any additional items to Information Sheet 15 that are not already listed there. This will give participants a list they can take home with them.

B. Discussion of "Quotations about Death" (30 minutes)

Introduce the discussion in a manner similar to the following:

"In this last experience we have identified many important and practical considerations in the death experience. Now as we approach the end of this workshop, it is important that we attempt to bring all our ideas together, examine what it all means, and instill in ourselves a future of action and creativity in order to better meet the demands of a fulfilled life.

"Read along with me as I read from excerpts by various authors, poets and philosophers as they discuss their feelings about death and hopes for the future. As I read these think about how these ideas relate to you and your life."

Hand out Information Sheet 16, "Quotations about Death," and read the quotations.

At the conclusion of the reading, ask the group to discuss the meaning of these quotations. The following questions might be used as a guide:

1. What ideas about life and death are presented by these authors? Do you agree with their thoughts? Disagree? How would you change their ideas?

2. Which of these ideas are most meaningful to you? Why?

3. How important is a sense of fulfillment or meaningfulness in life to how we approach death? Explain.

C. Complete Postests (15 minutes)

In order to measure the effectiveness of this workshop, my colleagues and I are asking you now to complete the same questionnaire that you completed six weeks ago. Please put your telephone number of social security number just as you did before so that we can keep your two tests together. Remember that there will be no attempt to identify persons with their answers. We only want to be able to keep an individual's responses together. Thanks for your help in this.

D. Handout booklet, "A Manual of Death Education"

E. Closing Discussion (10 minutes)

In the last few minutes of this workshop, and in an effort to bring closure to the session, ask the participants for any comments or questions they might have about the whole workshop experience. Ask them what they see as the specific strengths and weaknesses of the workshop. Leader should record these ideas on newsprint or chalkboard. At the conclusion of this experience, the workshop will be over.

Death the Fulfillment of Life

INFORMATION SHEET 15

Some Practical Hints about
Death Arrangements*

You should know or do the following:

1. Know the state laws on estate planning.
2. Have legal will prepared.
3. Have your attorney, insurance person, or minister keep a copy of the original will. These people will have quick access to your will and prevent unnecessary confusion.
4. Know where the deed to your cemetery lot is.
5. Know where your marriage licenses and birth certificates are.
6. Know your social security number.
7. Have a copy of previous year's tax returns.
8. Prepare complete biography.
9. Prepare list of close friends and family with addresses and telephone numbers.
10. Prepare list of your doctors and dentists in order to avoid confusion.
11. Prepare a list of your charity preferences.
12. Have safety deposit box in two names for easy access to the box.
13. Make your wishes known for the disposal of your body: science or burial.
14. Talk to and resolve with your spouse and family about funeral arrangements:
    a. Choice of funeral home
    b. Choice of funeral service, casket or cremation
    c. Choice of minister or officiating person

You should not do the following:

1. Keep the original will in a safety deposit box in only your name.
2. Fail to make plans for your estate and funeral.

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*Compiled from participants' suggestions in class on "Death and Dying" taught at Guilford Technical Institute, Fall 1977.

Death the Fulfillment of Life

INFORMATION SHEET 16

Quotations on Death

Fear in any form is essentially a thought. If we can eliminate the thought I fear death, then we can perhaps dissipate the fear of death itself.

The mainspring of human behavior is the attainment of "peak experiences" in which man is unified with himself, with others and with the world; and death is the ultimate unification experience--the culmination and fulfillment of life.—Gordon.

There is only one event in our life and in our universe that really counts, and this is death.—Maeterlnck

Life is real, life is earnest, and the grave is not its goal,
Dust thou art to dust returnest, was not spoken of the soul.
—Longfellow

The touching image of death
Presents no horror to the wise
And does not appear as the end
To the devout believer.
The former it forces back into life
And teaches him to act;
The latter is strengthened in the dark hour
By hope of future salvation;
For both, death becomes life.
—Goethe

The summer's flower is to the summer sweet,
Though to itself, it only live and die.
—Shakespeare

No being can fall apart into nothingness, the eternal is constantly astir in everything.—Goethe

Oh death, the loveliness that is in thee could the world know, the world would cease to be.—Bradley

As to death--to be exact--the true goal of life, I familiarized myself during the last couple of years to such an extent with this true and best friend of man, that its image contains nothing terrifying but on the contrary, much which is pleasing and consoling.—Mozart

Like a day well spent bestows pleasant sleep
So a life well used bestows pleasant death.
—da Vinci

Death, like birth, is a secret of nature.—Marcus Aurelius, Meditations

God made no death; neither hath he pleasure in the destruction of the living.—Apocrypha: Wisdom of Solomon

Death is the date of life.—St. Bernard, Sermon

Death, kind Nature's signal of retreat.—Samuel Johnson, The Valley of Human Wishes

Death's but a path that must be trod,
If man would ever pass to God.
—Thomas Parnell, A Night-Piece on Death

Death is but a crossing of the world, as friends do the seas; they live in one another still.—Wm. Penn, Fruits of Solitude

Death is but a name, a date,
A milestone by the stormy road,
Where you may lay aside your load
And bow your face and rest and wait,
Defying fear, defying fate.
—Joaquin Miller, A Song of Creation

When death comes to me it will find me busy unless I am asleep. If I thought I was going to die tomorrow, I should nevertheless plant a tree today.—Stephen Girard

Death remains the one citadel of mystery which autonomous man is compelled to surrender to his God.—Theodore O. Wedel, Christianity of Main Street

When Michelangelo, already well along in years, was discussing life with an old friend, the latter commented, "Yes, after such a good life, it's hard to look death in the eye."
"Not at all!" contradicted Michelangelo. "Since life was such a pleasure, death, coming from the same great Source, cannot displease us."
—Tremmler Werke publication, Germany

There is little to fear in dying and nothing to fear in death. The best thing to do about death is to do all you can to avoid it. Then forget it.—John Dollard, Victory Over Fear

A skeptical writer said some years ago that we ought not be troubled about death. In our unwillingness to die, he said, we were no better than a lot of peevish children, who, having played outdoors all day, were unwilling to come in at eventide. You might hasten to add that children are called in at the close of day with a purpose.—A. Gordon Nasby, "The House Not Made With Hands," The Expositor

Arthur Brisbane once pictured a crowd of grieving caterpillars carrying the corpse of a cocoon to its final resting place. The poor, distressed caterpillars, clad in black raiment, were weeping, and all the while the beautiful butterfly fluttered happily above the muck and mire of earth, forever freed from its earthly shell.

Needless to say, Brisbane had the average orthodox funeral in mind and sought to convey the idea that when our loved ones pass it is foolish to remember only the cocoon and concentrate our attention on the remains, while forgetting the bright butterfly.—Edmund K. Goldsborough, Sanctuary Magazine

Two children were overheard talking about the death of their grandmother. The five-year-old girl was asking her seven-year-old brother how "grandmother went to God." "Well," said the boy, "it happened this way. First Grandmother reached up and up and up as far as she could. Then God reached down and down and down. When their hands touched, he took her."—Gene E. Bartlett, Christian Century

Supplementary Materials for Use with the

Educational Intervention Module

on Death and Dying

Filmstrips and Cassettes	Available From	Cost
"Walk in the World for me," filmstrip of a three-part series; "Death and Dying; Closing the Circle," (3 filmstrips; 3 cassettes/ 61-102-549)	Guidance Associates 757 Third Avenue New York, New York 10017	$64.50
"Funeral Customs Around the World," Series SF 1972 - slides; cross cultural aspects of death and dying	Educational Perspectives Assoc. P. O. Box 213 Dekalb, Illinois 60115	33.00
"Perspectives on Death," 2 cassettes, 2 filmstrips (1) Toward an Acceptance (2) The Right to Die	Sunburst Communication Suite 83 41 Washington Ave. Pleasantville, New York 10570	59.00
Video Tape		
"A Dose of Reality," CBS - 60 Minutes Production	Audio Visual Services Pennsylvania State University Special Services Bldg. University Park, Pennsylvania 16802 (814) 865-6314	15.00 (rental)
Audio-Visual		
Recordings "Mortality" composed by Daniel Reed Album: The New Golden Ring, "Five Days Singing," Vol. 2	Folk Legacy Records, Inc. Sharon, Connecticut 06069	5.95
"Ain't No Grave Can Hold My Body Down" Album: Drive Dull Care Away, Vol. 1, Joe Hickerson	Folk Legacy Records, Inc. Sharon, Connecticut 06069	5.95

Audio-Visual (continued)	Available From	Cost
"O Death, Where Is Thy Sting?" From: "The Messiah" by G. F. Handel by London Symphony Orchestra and Chorus	Birdwing Records A Div. of Sparrow Records, Inc. 8587 Canoga Ave. Canoga RR, California 91304	$ 9.98 (purchase)
"Bury Me Not on the Lone Prairie" sung by Hedy West Album: Forty Great Folk Songs"	Radio Shack, Inc. Tandy Corporation Box 1052 Fort Worth, Texas 76102 500 One Tandy Center	3.99 (purchase)
"And When I Die" Album: Grt. Hits/Blood, Sweat and Tears	Columbia Records 51 W. 52 St. New York, New York	5.97 (purchase)
Booklets and Leaflets		
"On Being Alone"	NRTA/AARP 1909 K St., N.W. Washington, D. C. 20049	-
"Hospice of NC, Inc."	P. O. Box 11452 Winston Salem, NC 27106 (919) 724-7122	-
"Have You Made Your Will?"	Agricultural Extension Service Ricks Hall North Carolina State University Raleigh, North Carolina 27607	.15 ea. (purchase)
"Planning for Funeral Cost" (Series HE 221)	Agricultural Extension Service Ricks Hall North Carolina State University Raleigh, North Carolina 27607	.15 ea. (purchase)
"A Manual of Death Education" (1977)	The Celo Press Burnsville, North Carolina 28714	2.00 ea. (purchase)
"The Living Will"	Euthanasia Education Fund 250 West 57th Street New York, New York	-
"Bereavement--A Family Crisis"	Agricultural Extension Service Ricks Hall North Carolina State University Raleigh, North Carolina 27607	.15 ea. (purchase)